

Chuck Howell
Living with Kidney Cancer

My journey with RCC began in early Dec. of 2003. My wife Sue and I had just returned from So. Cal. after being there for the birth of our first grandchild, Gavin. Oh the plans I had for Gavin and Grandpa Chuck. The next morning I woke up and filled the toilet with blood, which really scared both of us. It was immediately off to Kaiser, where after a series of tests, I was diagnosed with RCC, and underwent a radical nephrectomy to remove my r. kidney, and a 17 cm tumor with Renal Vein involvement.

When you hear that Dr. tell you that you have cancer, your breath, and your heart stops for a moment, and in that moment three things flash through your mind.

- 1. Am I going to die?**
- 2. Am I ready, and what do I do now?**
- 3. How am I going to tell my family?**

Things moved so quickly that I didn't have time to think, between scans, tests, surgery, and recovery.

My son visited with Gavin, and I told him that he would not grow up and not know his grandpa, and I made a promise that I would beat this cancer, no matter what it took.

After two months of recovery, I was ready to go back to work and get on with my life; however, the cancer had other plans, and had metastasized into both lungs. I was told by my renal surgeon at that time that there was little treatment for RCC and given 90 days to live. I had never dreamt that this could happen to me, but there they were, five spots on a scan that would forever change my life.

Now my worst fears were coming true, I was going to die, and soon. Constant thoughts just seemed to fill my brain up.

- SO what will I do for the next 90 days? Do something crazy, like go skydiving, swimming with the whales, ride a bull named fu man chu?**

- **How would I tell my family, and what could I tell them?**
- **And what about my life long partner Sue, had I done all I could for her?**

Then we did what we do best, started planning on how to beat this damn disease! Thank God for the Internet.

After much investigation, support of my family, and two-second opinions, I met Brian Rini at UCSF who was starting a Phase III Clinical Trial using Interferon, and/or Avastin. I wanted on that trial! Now mind you, I had never even met my Oncologist @ Kaiser yet. When I first met him, I was ready to go to battle to get on this trial, but no one was certain of Kaiser's willingness to support this trial. I met my new friend, and Oncologist Dr. Fan Zhang, and he told me he had just arrived from M.D. Anderson, was very familiar with RCC, had administered IL2, and recommended I start the trial with Brian. I was ecstatic. However while waiting for approval to begin the trial, my gallbladder flared up, and we had to get it under control prior to treatment, that took 1 month .

I started the trial in March 04, and after 6 months I had to go off of the interferon due to side effects, and 18 months later, Avastin began to lose its efficacy, and I tried to get into the Trial with SUGENT as soon as it opened up. Two months later I underwent surgery to remove that gall bladder, which was now toxic, and my spleen. Prior to the surgical procedure I suffered total renal failure due to a drug interaction. I suddenly became very aware of how serious this was when the ER Doc asked me what my medical directive said about end of life treat options.

7 days after recovering from that little surprise, I danced at my oldest son's wedding, and then the day after I returned had the surgery, and recovered fully. Following that surgery I enrolled in a Phase III Clinical Trials using Sugent, then, Nexavar, ATN 161, and then applied for, and received approval for compassionate use of Torisel, which is still

working. I now have multiple lesions in both lungs, and in the esophageal area. However, I still believe I'll win.

January of 2008, I successfully underwent Cyber Knife treatment at UCSF by Dr. Kim Huang to shrink one large lung tumor, which was pressing on my heart and causing great pain. A recent cat scan shows 30% shrinkage of the radiated tumor, stability with some shrinkage of larger tumors, and no new metastases.

All of these treatments have caused side effects, some more toxic than others. Some can be life threatening, some milder. From a patient perspective, we really appreciate these drugs, and the fact that they give us hope, and in many cases keep us alive. Treatment of the side effects is very critical, because as we have learned, too many times we have to stop a successful treatment with a drug due to the side effects, so please keep up the good work of managing this critical component of treatment.

This journey has been very scary and at the same time one of hope. When I was first told my tumors had metastasized I went into shock, I'm not ready yet. I then contacted, and met a great person named Dr. Jack Bjornstrom, who ran the cancer support group at our church. I called Jack, and he and his wife Betty came right over and talked to us for hours.

As a classic A personality I felt like I'd drank 30 cups of coffee. I had to learn to let go of all of my life's stress and learn to relax. It was not easy for me to do. Jack told me that he felt that Cancer was the greatest gift God had ever given him. I told him he'd gotten too close to that radiation gun. Now, I fully understand what Jack meant, and I fully agree with him. Jack had throat cancer and the side effects were really tough. He retired from his practice and worked full time helping others with cancer; he was a very special and very inspiring man.

He guided me through the entire treatment process giving me great hope, advice, and love. He told me that while I might not be able to control the cancer, I could control how I reacted to it, and that I was in control, and to fight with every breath I had. But, that it was all my choice. Jack taught me how to dispel my fears of this disease, & live every day to its fullest. Jack even taught us how to pass on with dignity and grace when his time came. One of Jack's last words to me was that he was passing that torch on to me now and that I had to carry on the work of helping others. I try to carry on that wish each day. I've become part of the team who works with new patients, especially the few RCC patients, and work as a peer counselor for most new renal patients.

At Kaiser, I sing in the infusion center, tell jokes, harass all of the doctors and nurses, and hug and kiss them all. Patients who don't act like they're about to slug me, get hugs, and oh yes, they do give it back to me.

I also now have been blessed with four grandchildren and have three more grand daughters due in June. God has truly blessed me.

I recently worked with a very special fellow who was diagnosed with RCC last April. We became good friends, with more than cancer in common. I stayed with him and his wife through the whole process of treatment, and then with hospice, It was tough knowing some day that will be me, but what a sense of peace and love I felt when Marty passed, Jack did well in training me.

When I think of this journey, I can't help but think of the Verizon commercial which shows this crazy guy saying "Can you hear me now?", and then you see this huge group of people out there supporting his one call. That's what happens when you have cancer. You have a huge team of people wearing numerous uniforms backing us up. I call this one "Team Hope":

- **Drug Companies who develop and produce the drugs at great risk to them.**
- **Researchers who never give up in fighting for a cure.**
- **Doctors, Oncologists, Radiologists, Medical Imaging, Surgeons, Internal Medicine, Psychiatric, Pain Management, Infusion, Pharmacy, and Senior Management who support offering these normally very expensive treatments which all together keep us alive.**
- **And terrific support groups like this one where we can come together and share stories of living, treatments, side effects, and new drugs (hope) which are coming.**

This reminds me of another hero of mine Dr. Judah Folkman. In the 70's Judah had a theory that if you could somehow block the blood supply to a tumor, that it would die. Angiogenesis inhibition was in its infancy. People ridiculed Judah, but he persevered no matter what others said; this was a very long and protracted process. Judah also realized that when you take out the big tumor, it triggered the growth of the small ones. Many of are alive today because of the terrific efforts of this one simple man. I once called Judah up, assuming I'd never get through to him, and his staff took a message, and he called me back, and we talked for a 1/2 hour about treatment for RCC, I was honored. Dr Judah Folkman passed away this past year, and which of you sitting in this room may discover the next great leap in treatment.

People ask me how, and why I have been alive for the past four 1/2 years, I can tell them why;

- 1. The love and support of my best friend/wife Sue**
- 2. The love and support of my family and friends,**
- 3. I have a mission to complete,**
- 4. A great medical team, which comprises all of "Team Hope"**
- 5. God is not ready for me yet,**

I want to thank my wife Sue for her being there for me whenever I needed her. My oncologists, Fan Zhang, at Kaiser Santa Rosa, Jonathan Rosenberg, UCSF, Brian Rini, Cleveland Clinic, Fawaz Galani, Kaiser Riverside and David Minor. And this great group here at this meeting today.

I want to leave you with this simple prayer you have all heard:

**God grant me the serenity to accept the things I cannot change
The courage to change those that I can
And the wisdom to know the difference.**

**Live well, and thrive
God bless you all,**